

“My Future is Now”:

A Qualitative Study of Persons Living with Advanced Cancer

Ann H. Cottingham, MA, MAR,^{1,2} Larry D. Cripe, MD,^{1,3}

Kevin L. Rand, PhD,⁴ Richard M. Frankel, PhD^{1,5}

Corresponding Author: Ann H. Cottingham, MA, MAR, Regenstrief Institute, Inc., 1101 West Tenth Street RF-226, Indianapolis, IN 46202 Ph 317-274-9067 E-mail: ancottin@iu.edu

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¹Indiana University School of Medicine, Indianapolis, IN, USA

²Regenstrief Institute, Inc., Indianapolis, IN, USA

³Indiana University Melvin and Bren Simon Cancer Center, Indianapolis, IN, USA

⁴Indiana University-Purdue University Indianapolis, Indianapolis, IN, USA.

⁵Cleveland Clinic, Cleveland, OH, USA

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Abstract

Objectives: Advance care planning (ACP) enables individuals to deliberate about future preferences for care based upon their values and beliefs about what is important in life. For many patients with advanced cancer, however, these critical conversations do not occur. A growing body of literature has examined the *end of life* wishes of seriously ill patients. However, few studies have explored what is important to persons as they *live* with advanced cancer. The aim of the current study was to address this gap and to understand how clinicians can support patients’ efforts to live in the present and plan for the future.

Methods: Transcriptions of interviews conducted with thirty-six patients diagnosed with advanced cancer were analyzed using immersion-crystallization, a qualitative research technique.

Results: Four overarching themes were identified: I. Living in the face of death; II. Who I am; III. My experience of cancer; and IV. Impact of my illness on others. Twelve subthemes are also reported.

Significance of Results: These findings have significant implications for clinicians as they partner with patients to plan for the future. Our data suggest clinicians consider the following four prompts: I. What is important to you now, knowing that you will die sooner than you want or expected?; II. “Tell me about yourself,” III. “Tell me in your own words about your experience with cancer care and treatment;” and IV. “What impact has your illness had on others?” In honoring patients’ lived experiences, we may establish the mutual understanding necessary to providing high quality care that supports patients’ priorities for life.

Key words: Cancer, advance care planning, patient priorities for life, qualitative analysis

Introduction

Approximately 600,000 persons will die from cancer in the United States in 2017.¹ The time period between when a person is diagnosed with advanced stage incurable cancer and when a person transitions to end of life care, such as hospice, is a time when patients could benefit from discussions about life and treatment priorities, such as advance care planning (ACP). ACP is a foundational component of person-centered care²⁻⁴ for patients with cancer. Effective ACP occurs through a series of conversations between a healthcare provider⁵ and patient, ideally accompanied by family or surrogate decision-maker. Patients reflect on their personal values,^{6,7} life priorities,⁸ and practical concerns,^{9,10} and identify and document preferences for current and future care informed by these larger beliefs and goals.^{11,12} ACP increases patient and family quality of life,¹³⁻¹⁵ satisfaction with care, and concordance of patient care with patient wishes.^{5,13}

For many patients, ACP discussions do not occur.^{16,17} Reasons include patient reluctance to consider and discuss cancer or end of life issues,¹⁸⁻²⁰ lack of knowledge about the option, relevance, or advantages of ACP,^{3,21} access to health and hospital systems that include ACP as part of standard care, or access to clinicians prepared and willing to engage in the kinds conversations that lead to effective planning, including discussion of values, priorities, social and emotional concerns and practical needs.^{8,16,17,22-25} If the care plans for patients with cancer are to be fully informed, they need to be grounded in a patient's knowledge of prognosis and treatment option and, importantly, in the larger context of what that patient believes is meaningful in their lives.

A growing body of literature has examined the *end of life* wishes of seriously ill patients.²⁶⁻²⁸ However, few studies have explored what is important to persons as they *live* with advanced cancer, including their interests, concerns, and priorities. The purpose of the current study was to bridge this gap. Awareness of what is meaningful to patients living with a terminal

cancer diagnosis can help guide patients and oncologists as they consider care and treatment options that will impact the patient's present and future quality of life.

Methods

Participants

Patients who were 18 years or older, diagnosed with advanced cancer without a potentially curative treatment option, with an expected median overall survival of 6-12 months or less, and able to read and speak English, were eligible to participate in the parent study ²⁹. A total of 63 patients completed interviews, 36 of whom died within one year of the interview. We analyzed the interviews of the 36 patients who died within a year of their interview. The data set was limited to this group in order to capture the experiences of a group of patients who were more likely to have heightened awareness of their impending death. The average time between the interview and death for the 36 participants in this study was 223.13 days. Participants had lung cancer (42%), GI cancer (53%) and melanoma (6%), with an average age of 60.67 years. A slight majority were women (56%). Most participants were white (94%) and married (75%). The majority had graduated from high school (88%), were not currently working (70%), and had an income less than \$75,000 (56%). Most participants had not discussed their end-of-life care preferences with their oncologist (86%). (Please see Table 1). The study was approved by the Indiana University Human Subjects Institutional Review Board. All participants gave written consents.

Interview

Interviews were semi-structured. The interviewer asked each participant: 1) to describe their current life goals; 2) to describe their current treatment goals; and 3) to identify and discuss the life and treatment goals that were most important to them. Interviews were conducted in a private room, audio-recorded, and saved as digital audio files on a secure, password-protected computer. The interviews ranged in length from 13 to 35 minutes. All audio recordings were

transcribed, checked for accuracy, and given anonymous identifiers. The transcripts were then analyzed as described below.

Analysis

We used immersion crystallization as described by Borkan,³⁰ a qualitative method for identifying emerging themes, to analyze the interview transcripts. Members of the research team (AHC, RMF, KLR, LDC) initially read through three randomly selected transcripts to develop a provisional coding scheme, without using pre-established categories or theories. An additional four interviews were then selected at random and coded separately by AHC and RMF, both with training and experience in qualitative analysis. Complete sentences or phrases were the units of analysis for coding. Each unit was assigned to a single code. AHC and RMF refined the codes using the constant comparative method.³¹ The refined codebook was then applied to a second group of 4 interviews. The two researchers met again in person to discuss their codes, resolve discrepancies and come to consensus, after which it was determined that agreement had been reached in the coding approach. They continued to meet regularly, review each other's coding and come to consensus on all discrepancies until theoretical saturation was reached. Once all of the interviews had been coded, themes were identified and grouped into more abstract clusters that were discussed and refined by the wider team (AHC, RMF, KLR, LDC).

Results

Four main themes and twelve subthemes were identified in the analysis (See Table 2). These themes and subthemes elucidate what persons living with advanced cancer reported as important in their lives: I. Living in the face of death; II. Who I am; III. My experience of cancer; and IV. Impact of my illness on others.

Theme I: Living in the face of death

Patients frequently described the difficult experience of living with a terminal illness, “in between” health and the end of life. Patient responses to the experience of living with advanced

cancer varied, and three subthemes were identified: 1) Living now is important; 2) My approach to my terminal prognosis; and 3) Loss.

Subthemes:

1) Living now is important

None of the patients interviewed described themselves as dying. While patients recognized that their life trajectory was shortened, their focus remained on the life they are living now rather than their impending death. Patients commonly shared information about the people, places, things, and activities that were important to them as they lived their lives in the present. Many patients described spending time with family, such as visiting children or grandchildren. Some commented on enjoying personal hobbies, including listening to music, fishing or working on an old car. Patients also shared information about work they were undertaking around the home, such as installing windows, building a shed, and fixing the back patio. Some mentioned ongoing service work they found to be important, including building homes or volunteering at church. Rather than focusing on the end of their lives, these patients described living their lives here and now in ways they found to be meaningful and productive.

2) My approach to my terminal prognosis

Many patients expressed a particular personal approach to coping with cancer. Approaches varied significantly among patients. Some patients voiced a desire to accept their situation, noting that while others might become depressed or upset with a diagnosis of terminal cancer, they had intentionally chosen a positive response. Patients provided different reasons for their decision to remain positive. Some were satisfied with the life they had lived, stating that it had been good, productive or fun. Others felt it was important to be a positive person. Still others cited spiritual beliefs as the basis of their approach, reporting that they were ready to meet Jesus.

Some patients expressed different attitudes toward living with cancer. Several envisioned their current state as combat and articulated a desire to attack the cancer or fight

their disease. Some highlighted their lack of fear of the disease or of death, emphasizing that they were not scared by their diagnosis or approaching the end of life. A few patients highlighted their intention to avoid crying about their diagnosis.

For these patients, the attitude they chose to take toward their terminal prognosis appeared to be significant, a conscious stance that was the result of reflection and guided their day to day living with the disease.

3) Loss is important

Patients often reported that living with cancer resulted in an ongoing sense of loss. Some observed that having cancer had taken away their ability to control their lives. Ongoing medical appointments, unexpected changes in the course of the disease, or unanticipated responses to treatments were experienced as a loss of previous personal autonomy and ability to decide the course of their daily activities. Other patients expressed regret for the loss of specific roles. Some were no longer able to cook the holiday meals or paint the house. Many had given up professional work that had been an important part of their lives, such as farming, being a chef who worked 14 hours a day, or being an educator who trained teachers. These patients reported experiencing a feeling of loss for the pre-disease normal lives that they were no longer able to maintain and the control, roles or activities that still had significant meaning for them.

Theme II: Who I am

In nearly every interview, patients talked about factors foundational to their self-identify. Here, we found 3 subthemes: 1) Relationships; 2) Beliefs; 3) Life experiences.

Subthemes:

1) Relationships

Patients frequently mentioned those with whom they had close relationships. Many spoke about relationships with friends who were important to them during this time. Some shared the challenge of friends who were uncomfortable with their cancer diagnosis and reticent

to discuss their disease. Others noted friends who had gone out of their way to provide support, from sending cards to helping prepare farm fields for planting. One patient described a very close friend who had served as a model for her in living with her diagnosis of terminal cancer. The friend, who had recently died, had been well-prepared for her own death and the patient found in her a helpful example for how she might live her own life at this time. In each description, relationships with friends was important in the current lives of patients.

Most patients described relationships with family members. Perhaps surprisingly, given the severity of their illness, patients most often mentioned family members without reference to the illness. Many shared information about recent time spent with family or descriptive information about the lives of their loved ones. For example, one patient shared the excitement that a son had a serious girlfriend and might marry. Another shared the description of grandchildren ready to start college. Others mentioned siblings with whom they were particularly close, or parents, many of whom had died. Family support during illness was rarely referenced. When it was mentioned, it was most frequently in reference to a spouse who provided psychological support or investigated the patient's cancer or possible alternative cures.

In sum, relationships appeared to be an important source of meaning in the lives of these patient. During a time when it might have been anticipated that many of these individuals would begin to experience the solitude of advanced illness, connection with, but not dependence on, loved ones was a common theme.

2) Life experiences

Formative life experiences were mentioned by many patients as meaningful elements of their current lives. Patients recalled spending time in a monastic community, life lessons learned while working in a jewelry store, and the challenging consequences of a promise made years ago to care for an ailing brother. Many patients shared experiences that gave insight into their identity - who they were, what they liked, or what they had accomplished in their lives. The

experiences these patients shared continued to influence the way they understood themselves in the present.

3) *Beliefs*

Patients often described core beliefs that were foundational to their lives and their experiences of illness. Some identified personal philosophies that guided their lives, such as the belief in the importance of charity. More often, patients shared spiritual and religious beliefs. These beliefs provided an important context for the ways they understood their lives and their illnesses. Some provided hope, for example the belief that God would not let the patient down. Other patients revealed that their beliefs had been deeply challenged or their faith tested by the difficult experience of illness. For some patients, beliefs served to shift control over their life and death from the disease to a higher power. These patients shared a conviction that the timing of their death was not dependent on the trajectory of cancer but was in God's hands, stating that God alone would determine the length of their lives. Patients' beliefs provided an important frame for how they understood their disease in the day to day experience of illness.

Theme III: My experience of cancer

Some patients mentioned the medical aspects of their disease and its relation to their current life. Four subthemes were identified: 1) Disease; 2) Quality of life; 3) Relationships with healthcare providers; and 4) Independent efforts to achieve a cure.

Subthemes:

1) *Disease*

Patients' mention of disease was often brief and direct. They reported having stage IV cancer or a "tumor the size of a grapefruit." Patients did not comment extensively on the nature of their illness. Again, while patients acknowledged their terminal prognosis, none described themselves as currently dying.

2) *Quality of life*

Patients did describe their physical experience of illness and its impact on their quality of life. Some noted the negative effects of treatment on their lives, describing fatigue, debilitating illness, and a desire be done with treatments, such as chemo. Others reported feeling well, not sick, and surprised at their diagnosis. Subjective experiences of illness differed among patients.

3) Relationships with healthcare providers

Healthcare providers were not mentioned frequently. When they were mentioned, they were generally viewed as good allies in the treatment process and significant sources of support.

4) Independent efforts to achieve a cure

Finally, a few patients mentioned their own efforts, outside of medical treatment, to bring about a cure or manage symptoms. Many patients worked to stay healthy, eating well and exercising. Some went further, working to identify foods or alternate medicines that might help fight the cancer.

Theme IV: Impact of my illness on others

Some patients described the impact that their illness had on others. Two subthemes were identified in this theme: 1) Family and 2) Future patients.

Subthemes:

1) Family

Family members were most frequently mentioned solely in connection with the patient's life, and apart from the illness. There were a few exceptions where patients noted the impact their disease and treatment had had on loved ones, observing that it had caused stress for all those involved with the patient.

2) Future patients

Finally, some patients broadened their focus to include a concern for others who might someday have a similar illness. Several stated the importance of helping other patients or the medical community by participating in clinical trials.

Discussion

The goal of this study was to expand our understanding of what is important in the lives of patients with advanced cancer. The results provide important insight into patients' experiences of living in the face of a terminal cancer diagnosis. Nearly all patients talked about what was important to them *now*, including: living in the present, their attitude toward illness, family, spirituality, personal identity, and values. Most focused on what they wanted to do while they were living, such as repair a home, fish, or spend time with loved ones. No one characterized the present as an active stage or step in dying. In summary, the lens through which study patients viewed their disease was variable but circumscribed. Whether describing family, loss, life experiences, beliefs, or their own efforts to effect a cure, patients focused on living in the present and saw hope, opportunities for meaningful relationships, and possibilities for alternative paths to treatment and maintaining quality of life.

These findings have significant implications for clinicians as they partner with patients with advanced cancer to help them make informed care and treatment decisions. To ensure that decisions are in line with the unique personal context of each patient's life, our data suggest talking with patients about what is important to them now in the four key themes: 1. Living in the face of death; 2. Who I am; 3. My experience of cancer; and 4. Impact of my illness on others. Thus questions such as: I. What is important to you as you live now, knowing that you will die sooner than you want or expected?; II. "Tell me about yourself," (a question advocated by Platt³² as relevant to all patients); III. "Tell me in your own words about your illness;" and IV. "What impact has your illness had on others?" may be keys to making wise and informed decisions about care and treatment *with* and not *for* patients and their families.

Although this study offers rich information about what patients with advanced cancer find meaningful and important in their lives, it has some limitations. The study included a sample that was comprised largely of white, married, and college educated participants whose care was delivered at a single institution. The lack of diversity of the sample might limit the

generalizability of the study's emergent themes. Also, the sample size is relatively small, and the results might reflect a self-selection bias.

Despite these limitations, we believe the study is a good first step toward generating testable hypotheses and provisional guidelines for clinicians. Results may inform future research on patient and provider communication regarding life and care priorities, potentially expanding advance care planning conversations by enhancing the flow of meaningful dialog about these challenging subjects. Future directions will include exploration of the life priorities, values and goals of a broader demographic of patients, including patients from a wider range of age, race, disease type, education, and income.

In 1948, the World Health Organization defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease.”³³ Today medicine is still struggling to understand and enact the implications of that truth in the practice of healthcare. Despite a growing body of literature demonstrating the importance of incorporating patient perspectives, values, and preferences as core components of patient-centered care,²⁰ these conversations occur infrequently in practice.³⁴ If a goal of patient-centered care is to enable patients to make truly informed decisions about the final stage of their lives, it will be essential for practitioners to be skilled in conversations about the values, beliefs, and life priorities that inform those decisions. Recognizing and understanding that the future is now for many patients may be one step toward achieving that goal.

Author Disclosure Statement

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Table 1: Demographics

Characteristics	n	%
Total participants	36	
Gender		
Women	20	56.00
Men	16	44.00
Race		
White	34	94.44
Black/African American	1	2.78
Missing	1	2.78
Age		
M = 60.67 years (SD = 11.53)		
Employment Status		
Full time	6	16.67
Part time	3	8.33
Not employed	5	13.89
Retired	14	38.89
Student	1	2.78
Disabled	5	13.89
Missing	2	5.56
Education		
Some high school	2	5.56
High school	9	25.00
Some college	7	19.44
College graduate	6	16.67
Some graduate/professional school	3	8.33
Graduate school/professional school degree	7	19.44
Missing	2	5.56
Household Income		
< 15,000	2	5.56
15,001-30,000	7	19.44
30,001-50,000	5	13.89
50,001-75,000	6	16.67
75,001-100,000	9	25.00
100,001-150,000	3	8.33
Don't know	1	2.78
Missing	3	8.33

Cancer Type

Lung	15	41.67
GI	19	52.78
Melanoma	2	5.56

Partner Status

Married or living with partner	27	75.00
Unmarried (single/divorced/widowed)	8	22.22
Missing	1	2.78

**Have you and your doctor
oncologist discussed any
particular wishes you have
about the care you would want
to receive if you were dying?**

NO	31	86.11
Yes	3	8.33
Missing	2	5.56

Average time between interview and death
(days): M = 223.13 (SD = 120.45)

TABLE 2. What is Important to Patients Living with Advance Cancer?

Theme	Definition	Example Quotation
Living in the Face of Death		
Living life <u>now</u>	Patient focus on present priorities	<i>I'm going to live every day that I possibly can and ...I am going to be ok when I do die and I have done the things that I needed to do to have a productive life...c'est la vie. Patient 132</i>
Approach to living with terminal cancer	Description of patient's attitude toward living with a terminal disease	<i>I done been with it in the military, with it in my work life....married life, it's an accepted fact.... You know, death don't scare me. You know, I'm at peace...it don't scare me. Patient 125</i>
Loss	Expression of concern over current or future loss due to illness	<i>Well yes I've been working on an old house. It was built in 1876 and it takes a lot of time.... now that I know I'm out of time...That's not going to get done...Patient 167</i>
This is Who I Am		
Relationships	Mention of relationships with family, friends or colleagues	<i>I just buried a friend... I was there this past week and we were the best friends in the convent and she was 92, but her attitude was just...good for me... she was just so ready to die. She had such a rich life and I am so happy to be a part of that life too. 64</i>
Life history	Patient focus on past life events and experiences	<i>When I was 16 I was teaching yoga in my parents' kitchen... when I was 19, 20, 21, I lived in an ashram in Detroit... I have hitchhiked across the United States and Canada. Like I told everybody when I was 30, I said if I die today, I've lived more than what most people live in 2 lifetimes. Patient 106</i>
Beliefs and spiritual struggles	References to spirituality or religion	<i>I'm a very strong believer, and this...clears throat) this experience has really tested my faith I believe that my faith will become stronger. T10</i>
My Experience of Cancer		
Disease	Mention of cancer or treatment	<i>My cancer really is stage 4 . . . and it's metastasized.Patient 69</i>
Impact of disease on quality of life	Mention of the physical effects of disease or treatment	<i>The second time I took tarceva I took 100mg and I ended up having 12 holes cut in both or my legs from my calves down and I had MRSA in those and I am now on tarceva 25mg and uh, I haven't had any side effects like that. Patient 50</i>
Healthcare providers	Relationship with clinicians	<i>I think that your doctors... plays a lot in how you feel when you're in there in the hospital and if they show how friendly they are to you, it makes it easier for you to talk to them. Patient 5</i>
Independent efforts to achieve a cure.	Patient activities outside of institutionalized healthcare to find a cure	<i>I'm going to do everything I can within budget and that's reasonable [to effect a cure] and that I can easily do without, you know, traveling. Patient 22</i>
Impact of My Illness on Others		
Impact of illness on family	Description of impact of illness on family	<i>It's a tough disease and it affects everybody, not just the person going through it, but everybody in the whole family... It affects my kids, my grandkids, my wife, you know just, it affects everybody. Patient 61</i>
Impact of illness on future patients	Expression of actions or desires to help others	<i>Perhaps the treatments that I get will benefit somebody else someday...my treatments now are just experimental. Patient 8</i>